

Written Testimony of Mark Shaffer
On behalf of the Consortium for Citizens with Disabilities Rights Task Force
Before the Subcommittee on Health and the Environment
On March 6, 1997

Mr. Chairman and members of the Subcommittee, thank you for giving me the opportunity to testify today. My name is Mark Shaffer, and I am a law student in the Federal Legislation Clinic of Georgetown University Law Center.

I am testifying before you today on behalf of the Legislation Clinic's pro bono client, the Rights Task Force of the Consortium for Citizens with Disabilities. The Consortium, otherwise known as CCD, is comprised of over 100 national organizations representing 49 million Americans with disabilities.

While I am here today on behalf of my client, I would like to mention that I myself am a bone cancer survivor and an above-the-knee amputee. Thus, I am also here today as a person with a disability, who feels passionately about the issues I am about to address.

The CCD Rights Task Force takes no position in support of, or in opposition to, assisted suicide. The Task Force's membership runs the gamut, and its opinions on this controversial matter are as diverse as the membership itself. The Rights Task Force is, however, unified on what it believes to be the critical issue that underlies the assisted suicide debate but is too often left unsaid: the lack of access to services -- attendant care services, medical services, mental health services, and other support services -- for persons with disabilities and chronic illnesses. This is the issue I wish to address.

Members of the Subcommittee, the Rights Task Force comes before you today with the belief and understanding that you are genuinely interested in reducing the rate of suicide. Yet to date, most legislative efforts on this issue have been limited to bills that restrict the use of federal funds for that purpose. While these bills may make *some* difference in reducing the number of suicides in this country, the Task Force believes they will make a *small* difference at best. In order to make a *big* difference in suicide rates, we believe this Subcommittee must address the true *reasons* people seek assisted suicide in the first place.

Let me explain by example.

Consider the ventilator-dependent survivor of a motorcycle accident, whose insurance has long run out, and who is confined to an institution against his will. This individual could live in the community -- indeed, could be a productive and active participant in the community -- if only he had access to attendant services. Yet despite the fact that institutionalization is almost always more expensive than home health or attendant care, some public benefit programs only reimburse the institutions. Can we really blame this young man -- facing a life of involuntary confinement -- for considering an early death?

Or consider the case of a woman with cancer who is in intractable pain. The most current pain therapies available *could* alleviate this woman's pain, but these therapies are expensive, and not available to her. Either her medical coverage does not include this treatment, or she does not receive private health insurance but at the same time does not qualify for public assistance. Consider yourself facing a life of pain whose treatment you cannot afford. Decide for yourself what is the problem. Is it the availability of federal funds for assisted suicide that prompts you to think of killing yourself? Or is the real problem the lack of funds for proper pain management?

And then there's the young woman with cerebral palsy, who is also suffering from depression. But for her cerebral palsy, this woman would be a prime candidate for mental health care. But *because* of her illness, her depression is deemed "understandable" and "expected" and is summarily dismissed by her care givers. This despite the fact that the woman's depression could be effectively *treated*.

And last but not least, consider the individual who cannot afford a wheelchair, and the one who cannot afford a prosthetic arm, and the one who cannot afford the communication device he needs to speak. These devices make bearable and worth living those parts of daily life most of us take for granted.

Prohibiting people from using federal funds to *end* their lives is not enough. These people need public and private assistance so that they can *live* their lives.

Lest you think these are all hypotheticals, let me stress that my examples are all too real. Each is based on a true life story, where the individual in question sought to die. Indeed, when people lack access to the treatment and services that can make their lives worth living, they will continue to seek assisted suicide, regardless of whether federal funds exist to support it.

Thus, the Rights Task Force is not here today to argue in favor of or against the use of federal funds for assisted suicide. Rather, I am here today because the Task Force has taken you at your word that you wish to lower the rate of suicide among persons with disabilities and chronic illnesses. There is much that you can do.

You can ensure that Americans -- regardless of income level or disability status -- have access to quality palliative care. You can ensure that individuals with disabilities have access to attendant care and home health care, so that they can live in their communities rather than in

institutions. You can ensure that untreated depression is no longer mistaken as a desire to die. You can ensure that people receive the devices they need-- be it a wheelchair or a prosthetic arm-- that can enhance their quality of life.

The CCD Rights Task Force would propose legislation to fund programs and services providing alternatives to assisted suicide. The proposal provides that any person who (1) has been certified by a health care provider as having either an irreversible condition, a degenerative condition, a terminal illness, or as suffering from intractable pain; (2) satisfies a means test; and (3) is at risk of suicide, would be eligible for federally funded services, including mental health services and services necessary for basic living. A copy of our proposal is attached to my written testimony. This approach may not be cheap, but it *will* be effective.

I would like to close with one final story -- my own. As I mentioned earlier, I am a survivor of hard bone cancer. I was diagnosed with cancer at the age of 11, and my leg was amputated shortly thereafter. I am one of the lucky ones. My father had private health insurance; I had access to the best treatment, and the best services. Even then, things were hard. I remember when I was first getting used to walking with a prosthetic leg. I remember trying to walk up the hill to my house, and I remember falling every two or three steps. I remember wondering if life was really worth the effort.

I am here to say that life *is* worth the effort, but I can understand all too easily why others feel it is not. If I had not had access to the newest chemotherapies, if my doctors had not been able to manage my pain, or if I had been denied access to the recent developments in prosthetic technology I can only imagine what actions I might have considered.

Members of this Subcommittee, put your dollars where your heart is. Don't just offer us further restraints. Offer us the opportunity to live our lives. Offer us the opportunity to live our lives to their fullest capacities.

A Proposal to Fund Programs and Services Providing Alternatives to Assisted Suicide

I. A prohibition on the use of federal funds for assisted suicide does not address the reasons why people seek assisted suicide in the first place.

Members of both the House and the Senate have introduced bills that would prohibit the use of federal funds for assisted suicide. In explaining the purpose of the bills, sponsors of the Senate bill have stressed that federal tax dollars should be used “*to support and enhance human health and life*, not to promote the destruction of human life.”¹

The bills, however, address only one of these two stated goals. While the bills prohibit the use of federal funds for the *provision* of assisted suicide, they do not address the *reasons* why people seek assisted suicide. The bills, as currently drafted, would limit access to assisted suicide without taking steps to prevent people from seeking assisted suicide in the first place.

The need for such services is evidenced by real life stories. Larry McAfee, a 34-year-old quadriplegic, wanted to be taken off his respirator because he had “nothing to look forward to.” However, when he was given an electric wheelchair, a computer for drafting (he’s an engineer), and an accessible group home, he changed his mind. Another example is that of Elizabeth Bouvia. Ms. Bouvia, a person with cerebral palsy, checked herself into a hospital and informed the staff she wished to starve herself to death while taking physician-prescribed painkillers to mitigate her discomfort. While a court battle ensued over her right to die, she received counseling and support from private groups. By the time she had won the “right to die,” she decided she wanted to live.

The need for medical and mental health services is also supported by those who actually receive requests for assisted suicide. In its amicus brief in *Quill v. Vacco* (a case recently argued before the Supreme Court), the American Medical Association explained “. . . many patients today do not receive proper treatment for their pain, depression, or psychological distress. . . [O]ur society . . . should recognize the urgent necessity of extending to all patients the palliative

¹ 143 Cong. Rec. S1302, February 12, 1997 (Statement of Senator Ashcroft).

care they need and redouble our efforts to provide such care to all.”² The AMA further suggested that societal pressure to contain health care costs often inappropriately drives individuals to seek assisted suicide. “[T]he continuing pressure to reduce costs can only constrain the availability and quality of palliative care and support services that patients and families need. These limitations on the availability of proper care clearly can place pressure on patients to express a wish for suicide that they might not otherwise feel.”³

II. Any public policy in the area of physician-assisted suicide should include a proposal to fund mental health services and services necessary for basic living.

An amendment to any bill prohibiting federal funds for physician assisted suicide could establish an entitlement program that would fund psychological and medical services to a discrete group of individuals. To be eligible for such services, an applicant for federal monies would need to demonstrate that he or she: (1) has been certified by a health care provider as having either an irreversible condition, a degenerative condition, a terminal illness, or as suffering from intractable pain; (2) satisfies a means test; and (3) is at risk of seeking assisted suicide.

Significant overhaul of the health care delivery system would be needed to address *all* segments of the population at risk of suicide. A more targeted proposal, however, would address only those individuals who actually have unmet needs that, if met, might reduce their desire for assisted suicide.

To limit the proposal’s scope, services could focus on two categories: services necessary for basic living and mental health counseling. Absence of these services most often underlies an individual’s desire to seek assisted suicide.

(1) *Services Necessary for Basic Living:* Funds would be allocated to provide access to medical equipment, home care, attendant care, and/or pain management to individuals who have satisfied the eligibility criteria. Provision of such services could help prevent cuts in Medicaid, Medicare and welfare from being manifested in increases of the assisted suicide rate.

(2) *Mental Health Services:* Funds would be allocated to provide mental health services to individuals who have satisfied the eligibility criteria. Mental health services would include psychotherapy, psychotropic medications, and appropriate support services. Untreated depression would no longer be mistaken as a desire to die.

² Brief for the American Medical Association and et al. at 24, Compassion in Dying v. State of Washington, 79 F.3d 790 (9th Cir. 1996) (opinion from the Supreme Court pending).

³ *Id.* at 31.

Funds under this program could be provided directly to the program beneficiaries. Alternatively, public hospitals and community and migrant health care centers could act as financial intermediaries. Under any funding scenario, existing State, local, and nonprofit organizations should be utilized. There is no need to establish a new bureaucracy to manage this program.

Apart from the direct provision of services, the proposal should also include funding for demonstration projects. States, political subdivisions of States, and nonprofit agencies should compete for funds to establish demonstration projects focused on creative ways to reduce the desire and pressure for physician assisted suicide.

III. Conclusion

Sponsors of bills to prohibit federal funds for physician assisted suicide recognize that “institutionalizing physician-assisted suicide as a medical treatment would put many more patients at serious risk for *unwanted* and *unnecessary* death.”⁴ However, prohibiting the use of federal tax dollars for assisted suicide does not address the *reasons* why people seek assisted suicide in the first place. By funding medical services for basic living and mental health services, this proposal could ensure that undiagnosed depression and lack of access to support services do not cause Americans to choose assisted suicide.

⁴ 143 Cong. Rec. S1304, February 12, 1997 (Statement of Senator Nickles).

Providing Alternatives to Physician Assisted Suicide
The Position of the Consortium for Citizens with Disabilities' Rights Task Force

- **The Rights Task Force takes no position in support of, or in opposition to, assisted suicide.** The Task Force's membership runs the gamut, and its opinions on this controversial matter are as diverse as the membership itself.
- **The Rights Task Force is unified on what it believes to be the critical issue: the lack of access to services for persons with disabilities and chronic illnesses.** Persons with disabilities and chronic illnesses often lack access to attendant care services, medical services, mental health services, and other support services. Without these services, many individuals believe their lives are not worth living.
- **Persons with disabilities need access to attendant care, accessible housing, and other support services.** Many individuals with disabilities live in institutions not because they need to, but because attendant care and accessible housing are not available to them. These individuals could live in the community -- indeed, could be productive and active participants in the community -- but for the lack of services. Confined against their will, suicide often seems like the best escape.
- **Persons with disabilities often suffer from undiagnosed -- and treatable -- depression.** Because a person has a disability, his or her depression is often deemed "understandable" or "expected" and is summarily dismissed, even when it could be treated. Untreated depression is one of the leading causes of suicide.
- **Persons with disabilities often suffer from intractable pain.** Persons with disabilities often suffer from severe and chronic pain, yet lack access to quality pain management. Facing a life of intractable pain, suicide seems easier.
- **Restricting federal funds for assisted suicide is not enough.** If Congress wishes to lower the rate of assisted suicide, it must address the lack of access to services faced by persons with disabilities.
- **Congress should fund programs and services providing alternatives to assisted suicide.** Congress should provide federally funded services -- including services necessary for basic living and mental health services -- to needy individuals at risk of seeking assisted suicide.